

# The Center on Human Policy

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## EDITOR'S NOTE

The staff at the Center on Human Policy have studied the issues having to do with supporting adults with disabilities in living in the community for many years. Over the past four years, we have come to believe that the thinking in our field about community living for adults, especially for those with severe disabilities, must undergo a radical change.

This news bulletin addresses this need for change. It presents and summarizes some concepts about community living, tells the stories of a number of people who seem to enjoy their lives and the homes they have created, and introduces readers to agencies that are supporting people in individualized ways. It also presents resources for further exploration of the concepts introduced here.

This way of thinking requires setting aside the understandings one may have developed over years of working in the field. For many readers, it may require thinking differently about how the funding streams in their state could be put together to assist people in getting the support they need so that they can live where and with whom they want to live. Several of the people whose stories we tell, for example, are supported through funding sources that have traditionally been used in only one way (e.g., for foster care in a family or for group home living). We ask our readers to think about the people and their homes first, and about the funding that supports them second.



## Community Living For Adults

November 1989

### A HOME OF THEIR OWN



Darwin and Glen live with Randy, their paid attendant, in an apartment in a cooperative housing project in Madison, Wisconsin. Darwin moved to the community in late 1985 after spending most of his life at a state institution. He is a pleasant and gentle middle-aged man who has many friends. These include coworkers he met at his supported employment position with the state Department of Health and Social Services, neighbors

#### **Darwin's roommate, Glen, has lived with Darwin since Darwin's move from the institution.**

who also live in apartments in the co-op, and people who work for Options in Community Living, the agency that provides support for Darwin's living situation. He uses an electric wheelchair and a communication board. He communicates with picture symbols, and needs assistance with almost all of

Randy, Darwin, and Glen in front of their new home.

his personal care. Darwin loves to share jokes, using his communication board and body language, and he especially enjoys pointing at the pictures of the people who work with him and laughing about something that happened the day before or that he hopes will happen soon.

Darwin's roommate, Glen, has lived with Darwin since Darwin's move from the institution. Glen had lived in the institution where Darwin lived, and moved out a number of years ago. Before Darwin left the institution, Glen lived in several different places. When Darwin was ready to leave the institution, the Options in Community Living staff reintroduced them to each other and they agreed to try living together. They live with Randy, their paid attendant, who was recruited through Options. Randy has worked for them

since Darwin moved to Madison from the institution, and has lived with them since 1986.

Randy is a college student who is supporting himself through school. As a live-in attendant, his salary comes through two sources: adult foster care payments for Glen and Community Integration Program (CIP) payments for Darwin, who requires significantly more assistance than Glen. CIP is one funding source that has been used to support individuals formerly living in state institutions to move into the community.

### **In the co-op, there is a real community.**

Randy is away from the apartment at least two weekdays and two weekends a month. At these times, two other staff members, funded through CIP, support Darwin and Glen. Darwin and Glen, but not Randy, have their names on the lease, and they split the apartment expenses between themselves, with Randy paying for his share of the food. Randy is not expected to provide skill training or case management, but to be a roommate who also provides personal care and other kinds of assistance in daily living.

The options staff provide ongoing case management and training in daily living skills to Darwin and Glen, and a speech communication therapist also comes to the apartment to work with Darwin. Darwin, Glen, Randy, and an Options staff member hold house meetings twice a month to make sure things are coordinated, to decide who will do what for the upcoming week, and to ensure that life is going the way Darwin and Glen want it to go.

The first apartment Darwin and Glen lived in was nice, but it wasn't really theirs in the way the apartment in the co-op is. In the co-op, there is a real community. The people living there have a bigger stake in their living environment than do people in the typical apartment complex. The options staff helped Darwin and Glen find and arrange to become members of the housing cooperative.

This cooperative has a number of

unique features. It is a part of Madison's downtown community renewal effort, and is seen as a valued, desirable place to live. It is a mixed-income cooperative, in that there are three levels of rent, with one third of the tenants in each category. Tenants paying at any of the three levels (assisted, moderate, and market-rate) are found everywhere in the cooperative, and they all have the same types of apartments. Another nice aspect of the cooperative is that there are people of all generations. The people who live there do not build up equity in their apartments but are owners in the sense that they can stay as long as they like, they are all part of the decision-making in regard to how the cooperative runs, and they share the responsibility for managing it. There is a community garden in the back, and a lovely playground for the children. Four apartments on the first floor are totally

### **Randy is not expected to provide skill training or case management, but to be a roommate...**

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accessible, and others on that floor can be adapted for a person with physical disabilities. Darwin, Glen, and Randy live in one of the accessible apartments.

Both Darwin and Glen like to get out and do things. Darwin contributes to the co-op by delivering co-op mail like fliers and notices to his neighbors, and he regularly goes out to movies, coliseum events, parties, restaurants, and sports activities like bowling, swimming, skiing, and horseback riding. He, Glen, and Randy took a Wilderness Inquiry II trip to Yellowstone this summer; previously, they have gone on vacations and weekend camping trips together as well as separately. Glen likes doing many of the things Darwin enjoys, but he pursues some of his own interests as well.

Darwin and Glen have lives they enjoy, in a home that is really theirs, doing what they choose to do and exploring new vistas, new experiences, every year.

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## **NATIONAL POLICY INSTITUTE ON COMMUNITY LIVING**

In June 1989, the Center on Human Policy hosted a two-day national policy institute to explore issues and develop a statement supporting adults in living in the community. This policy institute was held as part of the Research and Training Center on Community Living through a subcontract with the University of Minnesota.

Three major themes emerged as critical as we move from the 1980s into the 1990s: the importance of living in one's "own home"; the context of the broader community in people's lives; and the extension of the independent living movement's concept of personal assistance to people with severe developmental disabilities. In the words of Gunnar Dybwad, "Any of these concepts fully applied will challenge the service system as it today exists."

*All people, regardless of severity of disability, can live in their own home in the community. People should have choice about where and with whom they live, control over their environment and how they spend their time.*  
Gail Jacob

One central and guiding concept in the 1990s should be that of "one's own home." While in the 1980s, we moved from "homelike" environments to "homes," the next decade should challenge us to examine the essence of what it means to be in "one's own home." A small, but important part of this movement should be the extension of home-ownership strategies to people with disabilities. Wherever people choose to live, support services should be available. No longer should home mean an "agency facility," but a place that represents the unique choices of the individual.

## OUT OF MY OLD LIFE AND INTO MY NEW ONE

By Michael Kennedy

*The statement should include a comment to community leaders...about inclusiveness and celebrating gifts and capacities of people with disabilities as community members.*

*John Winnenberg*

As we move into the 1990s, our focus should shift from people "being in the community to being a part of the community." The importance of relationships, the interaction between formal and informal supports and services, the roles of ordinary citizens in the lives of people with disabilities, and the contributions of people with disabilities to community life will become increasingly important. The 1990s should be a time to reevaluate the role that service systems can and cannot play in the lives of people with disabilities.

*People can live wherever they want to live if they have adequate supports.*

*Judy Heumann*

As we begin to support people in their own homes, we need to develop new ways of providing services that foster choice and decision-making on the part of people with disabilities. The concept of personal assistance, as defined by the independent living movement, may provide guidance about how to think about support services for people with severe developmental disabilities. In the 1990s, we should have opportunities to struggle with how people with disabilities can have "control over" their services and still move toward an interdependent society where "power is shared." The extension of the concept of personal assistance to people with severe disabilities should be a critical issue in the next decade.

For more information about the institute or about the statement supporting adults in living in the community, please contact Julie Ann Racino at the Center on Human Policy.



My name is Michael Joseph Kennedy. I am 28 years of age and I have cerebral palsy. I am one of four children. Because no services were available to assist my family and me, I was forced to spend 15 years of my life in state institutions. I would like to share with you my transition from institutional life to life in a real neighborhood.

I started in the West Haverstraw Nursing Home when I was about three years old. I did not like it there because of the treatment the residents received. We were not treated with the respect due any human being. Because we had physical impairments, many of us were assumed to be, and thus were labeled, mentally retarded. I believe that no matter how you are labeled, you should be given basic rights like decent treatment, education, and the right to live in the community. Later I was moved to Rome Developmental Center.

At Rome, I received much of the same treatment as at West Haverstraw. I later moved to Syracuse Developmental Center, where I lived from 1979 until 1982. Residents were not respected. We were given no choices and no freedom. Some people were abused, although it was better than at Rome.

In 1982, I heard about supported apartments being run here in Syracuse by United Cerebral Palsy, now known as ENABLE. The apartment program

**Michael (right) celebrates a birthday with his roommates, John and Gordon**

was just getting started and I wanted to be a part of it. [Editor's note: This program is an ICF/MR operated in an apartment building in Syracuse. Eight people live in two apartments adapted for people with physical disabilities and staffed on a 24-hour basis. The agency calls the program, which receives Medicaid funding and meets ICF/MR and state regulations, a "supported apartment" program.] I had wanted to get out of the institution for years and I finally saw my opportunity. In August 1982 I moved into the apartment. I had three roommates who also had a variety of disabilities. I lived at this apartment for six years. It was a great improvement over Syracuse Developmental Center. Now I was living with three other people instead of 20, the number of people I roomed with at SDC. But what I liked most was that it was in the community. I could be seen as belonging to the community, and I could experience being around people without disabilities.

A supported apartment might be a much better place than an institution. However, thinking about it now, it would have been best if I could have moved directly to a place of my own, with the support I needed. I think I

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could have made it if I had had the supports to make it work. In the supported apartment, I did learn a lot about living in the community, and I made new friends. After awhile, though, I began to feel very restricted in my growth. I was still feeling that my life was being controlled. I was not making decisions for myself. There were still instances when others made decisions for me. For example, I travel a lot for my job, and there were many times when I got home to find that plans that involved me had been made without asking me. I had to leave the apartment every day, even if I was tired after a trip (though they did occasionally make exceptions, if I made arrangements ahead of time). Also, I didn't get to choose who my roommates would be.

The staff at the apartment were excellent. They did all they could to create a homelike atmosphere. However, since we were funded by Medicaid, they had to develop and submit things such as personal goals for all the residents. The staff people did realize some of the state requirements were ridiculous and a waste of time, but they were unsuccessful in getting any changes made. They even went so far as to challenge Medicaid to cite them for violations instead of fulfilling certain requirements.

**It would have been best if I could have moved directly from the institution to a place of my own, with the support I needed.**

During my fifth year at the apartment, I began to feel strongly that I was ready to leave. Although on a much smaller scale, the apartment still retained some institutional features. For example, whenever I wanted to go somewhere, I had to tell everyone where I was going and when I was coming home. I am an adult and I felt that I was capable of using my own judgment regarding where I was going and when I would return. I felt I didn't have any privacy. I didn't feel truly free to make my own choices. I decided I was ready to move on. So I began to talk with our administrators

about how the apartment was better than the institution, but because of the regulations it was still somewhat institutional. I felt the apartment had no more purpose for me. I had gotten everything from the experience I was going to get.

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**For the first time in all these years, I've been able to host my mother in my own home.**

I actually moved into my own house on September 30, 1988, after six years in the supported apartment. I moved in with my friend John, who had worked with me at the supported apartment, and John's roommate, Gordon. We rent a house on Hawley Avenue which was bought by our landlord (also a friend of mine) specifically with us in mind. She bought a house she thought could easily be made accessible for me and my wheelchair. My name is on the lease for the house. I think it is important to say that neither of my two roommates are disabled. Our neighborhood is one which we chose for ourselves. The way this happened was that ENABLE had been working for a few years to start a service offering individualized supports for adults. They wanted a service that would combine a private residence and the supports necessary to assist a person with developmental disabilities to live there. [Editor's note: The options for community living through New York State's Office of Mental Retardation and Developmental Disabilities (OMRDD) are based on a continuum model and are quite rigidly applied throughout the state. ENABLE submitted a special proposal that permitted use of OMRDD's "family care" funding to provide individualized support for a small number of people who are assisted to live in their own homes.] I was the first person to benefit from this program.

The unique thing about this situation is that the agency did not set this up for us. It was the choice of the three of us working together. The agency was very supportive of our decision to live together in this particular house. Even when their own consultant advised them not to go with this house because

it would be costly to make it accessible, they backed us up and did a lot of work to make it accessible for me. Also, because the landlord is my friend, she has been very supportive and is still working on improving it, like enlarging the bathroom for me. I consider myself very fortunate that I was able to maintain my services such as visiting nurses, doctors, and therapists. I was able to carry those services over, with Medicaid funding. This was all my decision. I am currently in my thirteenth month in my house and everything is going fine.

The differences between my new living situation and my former living situations are numerous and immeasurable. I am now responsible for paying my own bills. Previously, I had never been entrusted with responsibilities. It was always assumed I could not be responsible for myself because I was disabled. Although I still receive financial assistance to pay my bills, everything is in my name. I am responsible for budgeting my money. My roommates expect me to pay my share of the bills. Another difference is that my mother, who lives more than 200 miles away, has been able to stay at my house for the weekend. She could never do that before, both because we didn't have room and she wouldn't have felt comfortable. For the first time in all these years, I've been able to host my mother in my own home.

Being responsible for my life led to my having control over my life. I make decisions for myself. I have equal say in everything that happens regarding our house. I make all the decisions that directly affect me. In the institution and supported apartment, my decisions were all made for me, often without my consultation. I did not have real control of my life. In my former living situations, recreation was decided by majority vote. I did not control my choice of activity. Now, I go out when I want and where I want. I don't need to ask anyone's permission.

As a consumer, I would like to propose that parents and professionals give people the opportunity to make personal choices themselves. I would also like the government to allocate more funding to support people in their own homes.

# INDIVIDUALIZED SUPPORTS FOR ADULTS: THE EXAMPLE OF THREE RESIDENTIAL SUPPORT AGENCIES

The Center on Human Policy has studied some agencies that provide individualized residential supports for adults with disabilities, including those with severe and multiple impairments or considered to have some challenging behaviors. Unlike many agencies that employ facility-based approaches, these agencies help people find homes and then build in the supports necessary for them to live there. The assumption is that people need stable, safe, and affordable homes in neighborhoods where they choose to live; that they should be involved in choosing where and with whom they will live; and that they should have choice and control over how they live and the supports and services they receive.

**...These agencies help people find homes and then build in the supports necessary for them to live there.**

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Options in Community Living (Madison, Wisconsin)

Options in Community Living provides support to 100 people, including some with severe and multiple disabilities, who rent or own their own houses and apartments throughout Dane County, Wisconsin. The agency has moved away from a "clustered apartment" approach whereby people lived in a cluster of apartments located in one apartment complex. Now people live where they choose and with whom they choose—sometimes by themselves, sometimes with roommates—and receive supports at these locations.

About 24 people served by Options employ live-in, paid roommates or personal care attendants to provide full-time support, using a variety of Medicaid and state funding mechanisms. For these people, Options acts as a broker—assisting them to recruit, screen, hire, supervise, and, if necessary, fire their attendants. Options also provides support to about 75 people who do not require live-in assistance but who may need intensive services and supports to remain in their homes.

The agency has three teams of "community support specialists" who provide support, case management, training, and other services. All team members know each person supported by their team and can give each other support and assistance as well as problem-solving help when a dilemma arises. One of the agency's priorities, in terms of support, is to assist people to become part of their neighborhoods and communities, and significant staff time is devoted to this area.

Centennial Developmental Services, Inc. (Weld County, Colorado)

The Residential Support Program of Centennial Developmental Services, Inc., provides support to 56 adults with disabilities, including a number of people who have significant impairments. This agency has also moved away from group home and clustered apartment arrangements to helping people live in their own homes with supports. The 56 people supported by the program live either by themselves or with others in apartments and houses, and receive significant but varying degrees of staff time.

The staff works in teams to assist people. Skills are taught within the context of typical daily routines and activities. A primary part of the staff's role is to help connect and involve people in their neighborhoods and community. The agency tries to recruit staff members who are themselves connected to the community, and the staff then use their own connections to increase the social networks and relationships of the people they help support. A strong sense of enthusiasm and spirit has been nurtured among the agency staff.

Residential, Inc. (New Lexington, Ohio)

Residential, Inc., is an agency which has also moved from providing group homes, and then a semi-independent and independent living program, to

supporting people in their own homes. The staff at the agency began to have concerns about how people were feeling about its group homes and other residential settings; the people were telling them that something was missing. Based on this, they decided to work from the idea that everyone should have their own home—either by themselves or with others of their own choosing. Staff members recognized, however, that access to housing was a problem not only for people with disabilities, but for many other residents of the community and surrounding county. As a result, some of the agency staff joined together with other members of the community to form the Perry County Housing Association, an organization designed to help promote increased opportunity for home-ownership for all residents of the county.

Along with this came a change in the administrative structure. In the past, the staff who made major decisions about a person's life had little or no direct support experience with that person. The agency recognized a problem with this, and changed to use "service planners." Each person who is supported by the agency is matched with a service planner (this match is based on people who know one another, get along, and work well together). The hours and duties of service planners are flexible, and depend on the individual's needs. Basically, the main responsibility of the service planner is to become involved with the person with a disability, draw in others, and help him or her obtain the needed assistance elsewhere.

The agency places emphasis on team support of people (trying to include at least one member of the team who does not work for the agency), building natural community supports for people, and assisting people to learn and grow through relationships, rather than special programs. From this agency's perspective, a key factor in support and integration is finding people who are willing to make long-term commitments to others.

## "WHAT'S FOR DINNER?"

**A key factor in support and integration is finding people who are willing to make long term commitments to others.**

### Summary

Five factors that contribute to the success of these three residential agencies are: (1) **small** size—despite pressures to expand, agency staff members are aware that they will lose their ability to provide quality individualized supports if they try to serve too many people; (2) **clarity** of **philosophy** and mission shared by the staff—there is a shared belief that all people with disabilities belong in the community, that the role of staff members is to do whatever they can to make this happen, and that the staff are working together as a team to reach this goal; (3) creativity in developing individualized supports—creativity in design and development of supports is based on the staffs knowledge of and relationship with the person, and their willingness to try different approaches in order to find out what works best for a particular individual; (4) flexibility of supports—the types and levels of supports can vary from one individual to another, and can vary over time for a given person as his or her needs change; and (5) commitment by the support staff to the individuals they support and to each other—an environment is nurtured wherein agency staff members feel an investment and ownership in the agency and have significant commitment both to the people they support and to each other.

Earl Spoden is a tall, thin, 68-year-old man with an air of dignity about him. He moves and talks slowly and seems to choose his words carefully. Earl has a sparkle of humor in his eyes and his face is very expressive. There is something about Earl that makes him very likable at first sight; he is a charming man. Since December 1987, Earl has lived on a farm in a rural area of Stearns County in central Minnesota. Earl lives with Ethel and Ebert Konz, a couple of similar age as Earl.

**"It was like it was meant to be. It is hard to imagine this place without him."**

Earl has spent most of his life in state institutions, nursing homes, and group homes for people with mental retardation. In 1930, when he was nine years old, he went to a state institution, where he lived for about 30 years. After that Earl moved to another state institution and later to a nursing home before he moved to a group home in 1981. In 1987 the county closed the group home where Earl was living in St. Cloud, Minnesota. Everyone moved to other places but there were problems in finding a home for Earl so he had to stay alone in the group home for a while. The local newspaper ran a story about Earl's need for a home. Ethel and Ebert Konz saw the article and invited Earl to come and live with them. Earl's case manager talks about their living situation in glowing terms: "Earl, Ethel, and Ebert are perfect for each other. Earl goes everywhere with them. Earl really likes living with them. This is the first time he has had a real home since he was nine years old."

Earl's living situation was made possible under the Stearns County Adult Foster Care Program and the Minnesota Medical Assistance Waiver. Although Earl receives assistance in learning and maintaining some domestic skills, he is not living in a program. He is living in a home that he shares with Ethel and Ebert. And as far as Ethel and Ebert are concerned, Earl is a part of the family and does not have to worry about moving again.

Ethel likes to tell the story about the first time she met Earl: "The first time I came to pick Earl up he just sat in the car like he had always done that. He turned to me and said, 'What's for dinner?'" Earl, Ethel, and Ebert all laugh when they tell this story. Then Ethel added, "It was like it was meant to be. It is hard to imagine this place without him."

Last year Ebert retired from the granite company where he had worked for about 30 years. When Earl heard that Ebert was retiring he decided that he should also retire from the day activity center where he spent his day. Both Earl and Ebert like pies very much, and now that they have both retired, Ebert and Earl make pies together and eat them as fast as they make them.

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**"Earl has become a part of the family. He is family."**

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Ethel says, "Earl has become a part of the family. He *is* family. He does everything with us. He also helps around the house. He sweeps the kitchen floor and does his own laundry." And Ethel continues, "Earl always goes grocery shopping with me and pushes the cart. He also helps me remember things. He is much better at remembering things than I am," Ethel laughs.

Earl is really involved in Ethel's and Ebert's family. This is a big family with a lot of grandchildren who all live nearby. Earl goes to all the family

by Julie Ann Racino and Steven J. Taylor

Community living for adults can be described from a variety of perspectives:

- An individual perspective. What does community living mean from the viewpoint of each person?
- A service system perspective. What are the best practices in the design of service systems and supports to enable people with disabilities to fully participate in community life?
- A community perspective. What roles do community members play in the lives of people with disabilities and what contributions do people with disabilities make to community life?
- A cross-disability perspective. What are commonalities across different movements (e.g., independent living, disability rights) that can bring us together?
- A policy perspective. How can federal, state, and local governments support the opportunity for people to live and participate in the community?
- A societal change perspective. What changes are necessary to improve the lives of all people, including people with disabilities?

Each of these perspectives is important and can provide insight into the full participation of adults with disabilities in community life.

This article examines directions in community living from a service system perspective. It compares and contrasts the traditional residential system for adults in the United States with an emerging approach to supports called an "individualized," "person-centered," or "housing/support strategy" approach. While this approach incorporates aspects of the "community," "independent living," "individual," and "societal change" perspectives, the primary emphasis is on how adults with disabilities can be supported better through changes in the design of service and support systems.

The Residential Continuum and the LRE Principle

The primary principle for the design of services and supports for people with developmental disabilities today is the principle of the least restrictive environment, together with its operation as a continuum.

The continuum can be classified as a line running from the "most restrictive" environment to the "least restrictive environment." The assumption is that people with the most severe disabilities will be served at the "most restrictive" end (i.e., institutions) and those with the mildest disabilities at the "least restrictive" end (e.g., independent or semi-independent living). As people acquire more skills, they are expected to "graduate" or "transition" to more independent settings.

For people with severe disabilities especially, the continuum concept has serious problems:

- People with severe disabilities get relegated to the "most restrictive" end of the continuum.
- The most restrictive placements, such as institutions, are not necessary.
- The continuum implies people need to leave their homes every time they acquire new skills.
- The most restrictive placements do not prepare people for the least restrictive placements.
- The continuum approach concentrates resources at the most restrictive end instead of toward typical homes.
- The continuum concept confuses restrictions of people's rights with intensity of their support and service needs.
- The continuum directs attention to physical settings rather than to the services and supports people need to be integrated in the community.

Characteristics of a Facility-Based Approach

The community living program in most states is primarily a "facility-based" approach to serving people with developmental disabilities. The program revolves around the living

arrangement, or facility, rather than around individuals. Thus, it is limited in both its flexibility and individualization.

By "facility-based," we mean that most community living programs have the following elements:

Agency owned or rented facility. Since providers own or rent the residential setting, they ultimately control who lives there. As O'Brien and Lyle (1986) point out, under this arrangement, "the person is a guest in someone else's home."

Licensed facilities. When agencies own and operate residential facilities, licensing is appropriate. However, by its nature, licensing often tends to limit people's choices and places decision-making power in the hands of people who do not live there.

Agency staffed. The staff are hired, paid, and supervised by the agency. Staff members are employed by and accountable to the agency, not the people receiving services. The staff member's relationship with the people is defined by conditions of employment set between the agency and the staff.

Staffing ratios based on the group. Staffing ratios and level of supervision are based on the group, not on individuals. To the extent that an individual has more or less intensive needs than others at the facility, he or she may not "fit into the program." Linkage of housing and support. People must live in the provider's facility to receive support services. Providers can be reimbursed for services only if the person lives in the community living arrangement.

Core funding tied to the facility. The funding is based on the facility and not the individual. Funding would not follow the individual if he or she moved to a new home.

Weak relationship between individual planning and funding. The rate-setting and individual planning processes proceed relatively independently.

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events like birthday parties and baptizing of the babies. He enjoys the children very much and they draw pictures to give him when they come to visit. Earl is most proud of a photograph that was taken when one of Ethel's and Ebert's grandchildren was baptized. The picture shows Earl, with a big smile on his face, holding the baby.

### **Earl is not living in a program. He is living in a home that he shares with Ethel and Ebert.**

Earl does a number of things with Ethel and Ebert. He helps Ebert gather firewood, he goes to bingo with Ethel, and the three of them go fishing together on the lakes in a boat owned by a member of the family. Earl likes to fish and he enjoys the boat rides very much.

Earl also goes to church with Ethel and Ebert. Everyone in the community and in the church knows him now. People greet him and chat with him when they see him at church. Some members of Earl's biological family live in the area. He met some of them at church and has been to visit them since. There had been limited contact between Earl and his family while Earl lived in the institutions and the group

**Earl (left), Ethel and Ebert telling stories in their kitchen.**

homes. Ethel has encouraged Earl's family to get back in touch with him so Earl really has two families now. He has become a part of Ethel's and Ebert's family, and his own family has become a part of his life again.

Earl has also made some friends in the area. He met one of them, Bob, through Ethel and Ebert. By now Earl and Bob have a friendship independent of Ethel and Ebert. Bob and Earl both like old movies and Earl goes over to Bob's house and they watch movies together.

Earl's passion is sports and he is a devoted Twins fan. Sometimes Earl goes to the Twins games with Ethel and other family members. At other times he goes on a whole day's bus trip to the Twins games with a group of people from the senior center. He now has a friend in the group, Delores, who is also a Twins fan.

Living with Ethel and Ebert has worked well for Earl because there was a good match between them. It is clear that integration into the Konz family has served as a link to many other community and family connections for Earl.

## **New Directions, (cont.)**

**Facility classification based on supervision needs.** Facilities are primarily classified as providing either 24-hour supervision or less **than 24-hr** supervision. Such a classification detracts from the question "What supports do people need to live in the community?"

### **Emerging Approaches: Supporting Adults in their Own Homes**

During a national search for programs demonstrating promising practices in supporting people **with** severe disabilities, we identified a newly emerging approach to supporting adults with developmental disabilities in the community. This approach has been called a "nonfacility-based," "individualized," "person-centered," or "housing/support service" approach.

This approach explicitly rejects the continuum concept, and the underlying LRE principle, as the basis for service design. Instead, it is based on the principle that adults have a right to live in a home in the community with whatever supports are necessary. Adoption of this principle on a large-scale basis would demand a fundamental change in the design of "residential services."

Four of the key characteristics of this approach contrast sharply with the facility-based approach described above.

### **Separation of Housing and Support Services**

One of the central features of this approach is the separation of housing and support. A manual prepared by Options in Community Living, a community support agency in Madison, Wisconsin, describes why it is important to separate housing and support: ...one agency should not provide both housing and support services. While we often advise and assist clients in finding, renting, and furnishing their apartments, Options no longer becomes the leaseholder or the landlord for client apartments. We want our clients to feel both

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control over and responsibility for their own living spaces. We also believe that receiving Option's services should not affect where clients live; our clients have a greater choice of living situations and know that beginning, ending, or changing their relationship with us will not put them under any pressure to move. This policy also frees us from the time-consuming and sometimes conflicting relationships involved in being a landlord. (Johnson, 1986)

Under a nonfacility-based approach to community support, regardless of where people live, they should have access to a variety of support services. While housing should be separate from support services, an agency might assist people in locating housing, signing leases, negotiating with landlords, finding roommates, purchasing furniture and furnishings, arranging for architectural adaptations, and obtaining housing subsidies.

There are several different kinds of housing arrangements. These include housing owned or rented in a person's own name; housing bought or rented by the parent or guardian on behalf of the person (but not occupied by the parent or guardian); housing jointly owned or rented by two or more people, one or more of whom has a developmental disability; and cooperative living arrangements. In addition, people with disabilities can live in existing homes or households (e.g., traditional foster homes) or in housing owned or rented by a corporation other than the service provider. To the extent feasible, people with disabilities should have access to the same range of safe and decent housing arrangements available to others in the community.

Support strategies must be individualized and flexible. These support strategies may include paid support, such as live-in, on-call, or drop-in staff employed by an agency and hired specifically to work with the person; paid roommates or companions who may be self-employed; an attendant

hired by the person with a disability; or a person who lives in the neighborhood and receives payment for some services, among others. Support strategies also include other approaches such as the use of physical adaptations (e.g., automatic door openers, emergency response systems), routine modifications (e.g., listening to a tape recorder) and the fostering of unpaid support.

#### One's Own Home

Another central feature stressed by a "housing/support" approach is the importance of one's own home. As opposed to residing in an agency facility, the emphasis is on a person living in his or her own home. First and foremost the phrase "one's own home" reflects feelings of "being in a safe haven," "of being oneself," "of being comfortable and at ease," "of making one's own decisions," "of belonging," and "of being in my/our place." These feelings of home are more likely to be associated with situations where people have a substantial say over their housing situation.

Increasingly, legal sole and joint home-ownership and leasing are becoming options for more people with disabilities. Instead of developing agency facilities, organizations are pursuing a variety of strategies to ensure the availability of accessible, affordable, and decent housing. These include the development of private cooperatives, the use of trusts for housing, financing through low-income tax credits, housing subsidies, and the purchase of homes through housing associations. Instead of residing solely in agency facilities, people with disabilities are living in places of their

#### Individual Assessment, Planning, and Funding

Another central aspect of this approach is a close tie among the three components of individual assessment, services planning, and funding.

All significant decisions in this approach are based on the individual person. This is a substantial departure from the typical residential development process where most of the significant decisions about housing and services (e.g., the size of the arrangement, the selection of the site location, the type of housing, the number of people, the level of disability, the number of staff members, the level of supervision, and the operating budget of the facility) are made prior to involvement of the person with a disability.

This new approach to assessment creates a picture of the uniqueness of the person "in order to determine what forms of help the community needs to plan, arrange, provide, and monitor to meet his or her needs" (Brost et al; 1984). Each plan will be unique, taking into account not only the characteristics of the person, but also the person's current life circumstances and the availability of alternative support strategies.

In this approach, financial issues are an integral part of the planning process for each individual. In common language, "funding is tied to the individual" (i.e., available wherever the person may live, useable for whatever services the individual needs or wants, and varying in amount based on the individual).

#### Choices and Decision-Making

This approach is also a step in the direction of greater control by people with disabilities in areas such as housing and services. In many ways, it represents the application of the fundamental premises of the independent living movement to people with developmental disabilities. In this approach, choices and decision-making by people with disabilities are of critical importance.

## DOING WELL IN WAHOO

These aspects of choice and decision-making extend not only to day-to-day events, but also to major life decisions. These include where and with whom a person will live, how and by whom supports will be provided, among others. For example, if a person is dissatisfied with his or her support worker(s), he or she can change service workers or agencies without being uprooted from living in her or his own home. As another example, people with disabilities can play a much greater role in selecting, hiring, and firing their individual support workers.

Full implementation of this approach will require that we become better listeners to the choices and preferences of people, including people who communicate in ways other than speech. In addition, if meaningful choices and decision-making are to occur, it is important that people with disabilities be accorded their full and equal place in this society.

### Future Directions

We are at the crossroads today in the development of residential services. The approach described herein has been pioneered by agencies such as Options in Community Living in Wisconsin and Centennial Developmental Services in Colorado. Selected aspects of this approach can also be found in a number of programs funded by the Title XIX home and community-based Medicaid waiver, in Canada's service brokerage model, in state-funded programs such as Michigan's supported independence program, and in the independent living and mental health movements. We need to learn from these experiences and must work together to ensure that people with severe disabilities will have a right to both a home and to the services and supports they need. At the same time, we must also continue to examine the limitations of a service system approach to people's lives.

Delores and Leroy Woodruff are a married couple in their forties who live in a small house in Wahoo, Nebraska. Delores and Leroy have been married for seven years. They have a good marriage and get along well with each other.

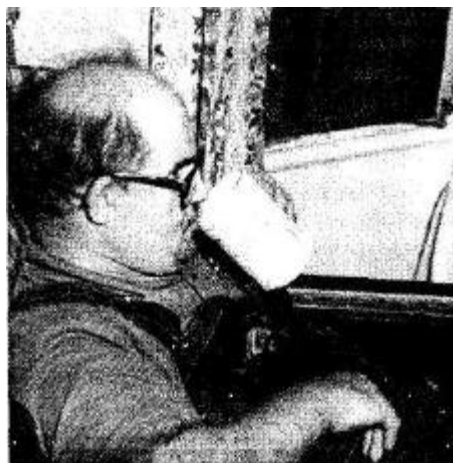
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**They have a good marriage and get along well with each other.**

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According to people who know them, Delores and Leroy didn't always get along with other people. Leroy used to live in an institution and then a group home. Delores previously lived in a group home. She had some behavioral problems while she was there. Delores is diagnosed as having both mental retardation and mental health problems. Because of her mental health problems Delores has been hospitalized occasionally. She has periods where things are not going so well, but she also has good times.

Delores and Leroy would probably not be doing so well in many places around the country. They would probably be living in institutions or group homes. If they were left on their own, they would be living in sub-standard conditions and maybe wandering the streets. They are doing well in



Leroy relaxing in the living room.



Delores fills her coffee cup.

Wahoo, however, with support from Region V, a community service agency in the area surrounding Lincoln, Nebraska.

**Delores and Leroy would probably not be doing so well in many places around the country.**

The support Delores and Leroy receive is individualized to meet their needs. Each day a Region V staff person comes in from 2 p.m. to 10 p.m. (one staff person on weekdays and another on weekends). The staff person cooks for them, makes sure their house and small yard are clean, helps them with budgeting and personal hygiene, and works with them on developing skills.

Delores and Leroy rent their house themselves, although Region V helped them find it. Delores's and Leroy's house is not a "homelike setting." It's their home.

When we first met Delores and Leroy in 1985 they had only been married for three years and were having some problems with their marriage. That hardly made them unique, and they received marriage counseling regularly. Now their marriage is going very well

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**(Their) house is not a "homelike setting." It's their home.**

and their relationship has grown closer and stronger. They don't need marriage counseling any more. In 1985 Delores and Leroy were living in a trailer. In 1987 they moved into their little house and are very proud of it.

When asked whether people living in their own homes receiving support from Region V ever kick staff out, a Region V administrator answered: "Yes, that happens." When asked what happens then, she said: "Oh, the staff member will go away for an hour or two, and by the time they go back, the people are sorry about the whole thing and apologize."

Leroy had a hip replacement a few months ago. A Region V administrator said: "We knew he was suffering but we didn't know just how badly till after he had the operation. He is recovering very well and feels much better after the operation."

It has been a very encouraging experience to keep in contact with Delores and Leroy and see the positive changes in their lives and how their lives have improved over the years since they moved out of the group homes. We agree with the administrator who said, "Things have never been better for Leroy and Delores." There are problems, but they are dealt with as they come up, by giving them extra support or by making changes in the support they get. Delores and Leroy are a part of the problem-solving process, and have responsibility for their lives together.

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**'Things have never been better for Leroy and Delores.' ???**

Delores and Leroy are indeed doing well in Wahoo. They have something that too few people with mental retardation seem to have. They are living with dignity.

*The following expands on the article, "New Directions in Community Living for Adults with Developmental Disabilities," and deals with some of the issues it raises.*

### Housing Considerations

Homes should be typical **for** the community: In most communities, most people live in apartments, condominiums, houses, cooperative housing projects, or mobile homes, not in specially-built facilities designed or remodeled for groups of people with similar needs. People with severe disabilities should have the same range of typical housing options available to them as do other community members, and any of these housing options can be called "home."

Homes should be typical in size for anyone with like wants and interests: Depending on their racial and ethnic group membership, single adults in the United States typically live with one or two roommates of their choice or with their families. Married people typically live in homes of their own. People with disabilities, whether single or married, should be supported to live in homes by themselves, with one or two roommates, with their parents or extended family, or with spouses, depending on their own interests and wishes. People making any of these choices should not risk loss of material or human service system support.

Homes should be in localities that make sense for the people who will live in them: People have many rationales for choosing the neighborhood they want to live in. Some want to live near their families, near their jobs, or near particular kinds of community facilities. Others may want to have some distance from people, and prefer to live in a sparsely populated area where they have plenty of open space. People with disabilities should have choices about where in a commu-

nity they prefer to live, and should be helped to find housing in areas that most closely match their preferences.

### Residential Agency Supports

A major new role of the residential agency is to support: Administrators of residential agencies, and the state developmental disabilities offices that fund them, traditionally view the residential agency as a provider (i.e., planner, organizer, controller, deliverer) of a set of services. From this perspective, the need to maintain efficient and effective service delivery, convenience, and accountability requires the organization to maintain control in the form of decision-making authority over what happens to each of the people it serves. The person is often expected to adapt or subordinate his or her needs and wishes to fit the resources the agency makes available. When this is not possible, or when the person's needs change, the person may be discharged or transferred to another setting.

**People making any of these choices should not risk loss of material or human service system support.**

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True individualization, on the other hand, requires agencies to assume a supportive role. This role means that the agency assists the individual to fulfill his or her own hopes and wishes, to develop skills and interests, to attain wellness and safety, and to participate fully in community life, which should include relationships with friends and family members. This assistance or support is given with the full involvement of the person in the planning and decision-making, and with awareness and respect for his or her choices or preferences.

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Another major role of a residential agency should be to commit itself to the people it supports: As mentioned above, residential agencies traditionally require individuals to fit agency criteria, and may discharge or transfer people whose needs or wishes do not mesh with the agency expectations.

The new way of thinking, on the

**People with disabilities should have choices about where in the community they prefer to live, and should be helped to find housing in areas that most closely match their preferences.**

other hand, stems from the basic principle of personal and agency commitment to each individual. Residential, Inc., for example, puts major emphasis on recruiting and supporting service planners, staff members who will make a personal commitment to one person with whom they work. The agency's commitment is that no one supported by the agency will lose support for as long as it is wanted, and that changing needs mean changes in the intensity or type of support. But agency commitment to the person, while seen as necessary, is not viewed as enough. Each person also needs people who have a personal commitment to him or her, and the agency must help to find those people.

The residential support staff may have new roles: Traditionally, the residential support staff have been viewed as direct service providers whose job was to carry out the individual's program plan, to manage the household operations and routines, to provide personal care, and to develop caring relationships with all the people for whom they were responsible. With individualized services, the role of the residential support staff may be entirely different, even though some of the responsibilities or tasks may be the same.

One agency may envision the essential role of the residential support staff

as discovering what the person wants and needs and assisting that person in attaining it. In another agency, the residential support staff may be asked to "dream with" the person and to support the person in realizing his or her dreams. Still another may speak of empowering the individual through support that encourages self-determination and self-control.

The residential staff working for any of these agencies may engage in the following types of activities: teaching daily living skills; assisting in problem-solving; providing personal care; assisting the person to recruit, hire, supervise, or terminate a care attendant; supporting the person's participation in community activities or organizations; encouraging the development of relationships with neighbors, coworkers, and fellow members of organizations or classes; assisting in creating and following meaningful daily routines; taking a vacation with the person; household maintenance activities; and other such undertakings.

It should be evident that many of these are the same types of tasks performed by staff in more traditional agencies. The difference is that the person receiving support is seen as the focal agent — his or her needs, hopes, and wishes are what are supported by the staff person's work, not the needs and requirements of the residential agency. Often, the person receiving support and the staff person or persons working with him or her are seen as a team. Together they decide what hours the staff person(s) will work and what the staff person will do.

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**...the agency assists the individual to fulfill his or her own hopes and wishes.**

Support is given when and where it is needed: In many conventional agencies, people receive services at times and places that are convenient for the agency or that meet certification requirements but which result in untypical daily routines and rhythms. Such services may include personal

care routines, meals, and household maintenance activities such as shopping, cleaning, and laundry, all of which are necessary for living in the community. In conventional agencies, however, where the recipients of services are grouped together, we too often find that skills are taught out of context and that meals and personal care routines are conducted at the times when the staff can be available (e.g., bathing at 8:00 p.m. so that others can bathe later on: packing lunches in shifts; having to do one's laundry on a set schedule so as not to conflict with others' laundry days).

**The new way of thinking, on the other hand, stems from the basic principle of personal and agency commitment to each individual.**

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Often, especially in group settings, people spend a great deal of time waiting for the next activity to occur.

When supports are individualized, people's daily routines fit their own rhythms and preferences. People need not arise two and a half hours before work just so that they can all have a turn in the bathroom or in the kitchen, nor do they have to bathe at a time when they might prefer to be away or watching television. People can make individual schedules for the day, based on their own wishes and needs, and can make spontaneous decisions about leisure activities. Whether or not a person has a severe disability has little impact, in a person-centered living arrangement, on the number or timing of his or her routines, because the staff and the person will have worked together to develop a schedule based on his or her preferences and needs.

"Programming" takes place naturally and within normal daily routines: Residential agencies that provide individualized supports for

people also tend to feel that learning should take place in the settings, and at the times, when the skills to be acquired will be used. Thus, instead of teaching money-handling with play or real money in the home, the support staff may teach these skills at the bank or in a store or restaurant. Cooking for oneself will be learned in the context of meal preparation, and may involve preparation (through full or partial participation) of all aspects of

**...that no one supported by the agency will lose support for as long as it is wanted.**

the meal. Instead of learning to prepare part of a salad for four or six people, the person will help with the whole salad and the main dish for himself and his roommate, for example. Likewise, cleaning and laundry and other household maintenance activities will be learned and practiced at times and in the places where they will need to be used.

The residential support staff are deployed differently than in conventional agencies: In conventional agencies, the staff who support people usually work according to a shift schedule; depending on the type of program, they may work eight-hour shifts or shifts of shorter duration (e.g., stopping in on a supported apartment for a few hours two evenings a week). The staff are there based on schedules developed by the agency, and may be present many more hours a week than are needed by a large number of the people served by the agency, just because these people have not moved to a less restrictive place in the continuum of services the agency offers.

Programs offering individualized support deploy staff in ways that make sense to the staff and the people

supported. Options in Community Living and Centennial Developmental Services have created a team concept, whereby two or more staff members support each person and come to know him or her very well. Residential, Inc., tries to have one primary person, the service planner, who supports the person but is backed up by another person whose role is similar to the service planner's but who can push the agency and the state system in ways the service planner cannot. In each of these agencies, the paid staff work with the person to determine the types, times, and intensity of support the person will need or want. The agency sees its role as supporting those arrangements, not imposing other arrangements on people.

Support for staff members is high in agencies offering individualized supports: Agencies offering individualized living supports find many ways to support their staff. They tend to involve their staff in planning and decision-making at a number of levels, giving staff members a sense of control over their work. They tend, because they know that situations constantly change, to encourage and support creativity and flexibility. They tend to see the agency's role as that of enabler; if a person (staff member or person

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**...people's daily routines fit their own rhythms and preferences.**

being supported) needs something, the agency's job is to cut through the red tape and other barriers that might prevent that need being met. They create an atmosphere of mutual support, so that the staff grows to rely on each other and on the agency. The staff training may be organized based on expressed needs of the staff, often on an individualized basis so that the staff learn how to work with and support one particular person rather than a generic "person with physical/medical/behavioral needs or disabilities."

**Today, we know that there are limits to what service agencies can do...**

Relationships with family members, neighbors, and friends are promoted and supported: Too often, human service agencies have forced people into a dependent "client" role that has the effect of cutting them off from family and typical community members. Often, even their friendships with other people with disabilities are not supported. Today, we know that there are limits to what service agencies can do; agencies can meet some needs, such as the need for material support, coordination of services, or assistance with daily living, but cannot meet the need for connectedness in the community. This need can only be met through family, neighbor, and friend relationships and through association with people having common interests. Agencies that are aware of people's needs for connectedness or belonging will find ways of assisting people to make and maintain relationships of many kinds outside of the human service system. This sounds "messy" and difficult, from the agency's point of view, because it requires new kinds of efforts and skills, a willingness to set aside plans and schedules to have time for a friend, neighbor, or family member, and a letting-go of exclusive knowledge of or control over a person.

**Conclusion**

The differences between the "person-centered" or "housing/support strategy" approach and traditional residential service approaches are evident. Agencies across the United States and Canada are making the changes and are learning, in the process, that everyone, regardless of the severity or complexity of disability, can live and thrive in the community.

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## MR. JORDAN

People who are described as having "severe behavior problems" are most often subjected to increasingly restrictive environments and experiences, along with negative, punitive, aversive treatment and loss of meaningful social relationships and personal autonomy.

Until recently, the above description reflected Mr. Jordan's experiences and life quite accurately. He had lived in institutions most of his life and had, for nearly 40 years, engaged in multiple forms of severe and life-threatening self-abuse. In 1986, Mr. Jordan moved out of the institution and into a supervised apartment. He now has a full-time job in the community and he virtually never engages in self-injurious behaviors. We hope that Mr. Jordan's story will inspire people who want to help people with challenging behaviors live with dignity and lead a meaningful life in the community.

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**The psychologist noticed that during these walks off the unit Mr. Jordan did not engage in self-injury.**

Mr. Jordan (not his real name) is 46 years old and lives in Syracuse, New York. He has been labeled as having severe mental retardation and mental health problems. He was institutionalized in 1949 when he was 6 years old. He does not speak, but uses vocal sounds, gestures, and pointing to tell others what he wants. Since he was in his preschool years he had been reported to have severe self-injurious behaviors, which at times were health- and life-threatening and often resulted in hospitalizations, extensive tissue damage, serious malnutrition, and drastic weight loss.

Some of the serious behaviors noted in Mr. Jordan's institutional records over the years include frequent vomiting, ruminating, head banging, head hitting, scratching and rubbing, picking and tearing off fingernails and toenails, body slapping, eye poking,

ear poking, and body banging. On the average he received medical treatment monthly at the medical clinic at the institution or the hospital emergency room for injuries caused by his self-abuse. Mr. Jordan also reportedly

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**It was as if he used these increasingly negative and life-threatening behaviors to try to gain control in the institutional environment where he, in fact, had no control.**

yelled and cried, frequently hit and kicked other people, spat, vomited and excreted on others.

Because of Mr. Jordan's behaviors he rarely attended the day program outside the institution. In fact, he seldom left the institutional living unit except to receive treatment for his injuries.

A variety of procedures, both positive and aversive, had failed to modify Mr. Jordan's behaviors in any significant way within the institutional environment and the most serious and life-threatening behavior, vomiting, escalated dramatically in 1985 and resulted in serious weight loss; his weight dropped down to approximately 90 pounds.

When Mr. Jordan injured himself, he was physically restrained until he was calm. Restraint was used frequently and sometimes resulted in injury to the staff as well as to Mr. Jordan. Because vomiting was the most serious problem, Mr. Jordan was released if he vomited while being restrained.

Mr. Jordan's staff psychologist at the institution devised a pro-active behavior treatment program for Mr. Jordan, in which he would be taken for 10-minute walks off the unit as a reward for not engaging in self-injurious behavior. The psychologist noticed that during these walks off the unit Mr. Jordan did not engage in self-injury. The program was revised so that he would have longer periods of

time spent away from the institution in a variety of community environments. Continued improvement confirmed people's suspicion that there was a relationship between the self-injury and the institutional environment. The staff also reported that they avoided using aversive procedures, such as restraints and time-out, because they considered them to be responsible for the increased vomiting. In fact, Mr. Jordan seemed to be using self-injury for a variety of functions, including getting attention and avoiding tasks. It was as if he used these increasingly negative and life-threatening behaviors to try to gain control in the institutional environment where he, in fact had no control.

As a result of these observations, the psychologist developed an alternative positive intervention program for Mr. Jordan with the assistance of a profes-

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**...he was actively involved in making choices and decisions about his daily life and changes in his program.**

sor from Syracuse University. The alternative plan provided Mr. Jordan with appropriate and long overdue choices and control of his daily life. The aversive procedures, such as restraints, were eliminated from his program.

In contrast to past procedures the emphasis of the alternative intervention was to implement extensive program and placement changes that would completely change the current stances and environments associated with his self-injurious behaviors and replace them with meaningful community-based alternatives.

The alternative intervention plan consisted of four major components (1) A radical change in the continuums and situations associated with self injury. This included a move from

*Continued on page 15*

institution to a supervised apartment in the community; (2) To replace self-injurious behaviors over the long term, Mr. Jordan was instructed in positive alternative behaviors and participated in various functional, community-based activities, including employment; (3) Rather than imposing alternative activities and community living upon Mr. Jordan (like institutional living and other activities had been imposed upon him earlier), he was actively involved in making choices and decisions about his daily life and changes in his program; (4) Back-up crisis management procedures were instituted to deal with any self-injurious behavior.

The significant relationships established by Mr. Jordan in the past were also of primary concern. Attempts were made to reintroduce him to his family, and his primary direct-care staff person at the institution, who had also become his friend, was asked to move with Mr. Jordan to the apartment. A second full-time staff person was hired prior to his move in order to establish a positive relationship before the move from the institution to the community.

At the beginning of October 1986, Mr. Jordan moved to the house in the community. Two other men, who also have disabilities, live in the house. Mr. Jordan participated actively in preparing for the move. For example, he helped plan, buy, and arrange all necessary personal items prior to moving. He packed his belongings and placed them in their appropriate place in his new home. He also participated in selecting furniture for the house and choosing which bedroom would be his.

Mr. Jordan also completed two vocational training rotations at job sites in the community doing clean-up work and got a full time job in the community.

As this is being written, Mr. Jordan has been living in the community for almost three years, and the dramatic improvements in his life and behaviors have maintained during this time. He continues to work a full day in the community and no longer requires the one-

on-one staffing during the workday or evening hours at the house. He participates actively in all household chores, including cooking, cleaning, laundry,

**As this is being written, Mr. Jordan has been living in the community for almost three years...**

and shopping. He participates in social and recreational activities and attends parties, movies, picnics, and other social functions in the community. His overall health has improved and he has gained weight. Mr. Jordan is responding positively to new demands that reflect a more meaningful life-style and is learning to make choices and exercise appropriate control of his life.

Mr. Jordan's story teaches us the importance of providing the same kinds of resources and efforts to implement non-aversive community-based supports as those used in restricted group settings. In Mr. Jordan's case, all previous efforts to modify his self-injurious behavior within the institution had been unsuccessful; in fact, his condition associated with the aversive consequence program was judged life-threatening. A longstanding behavior pattern was finally reversed by providing meaningful experiences that should have been in place for anyone in any good service delivery system as a part of a reasonable life-style.

For a more detailed description of Mr. Jordan's story, see Berkman, K.A. & Meyer, L.H. "Alternative Strategies and Multiple Outcomes in the Remediation of Severe Self-Injury: Going "All Out" Nonaversively." *The Journal of The Association for Persons with Severe Handicaps*, Vol.13, No.2, 1988, pages 76-86.

#### About This Bulletin:

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## ??? RESOURCES ???

The books, articles, and manuals listed below address various aspects of the "person-centered" or "housing/support strategies" approach to community living for adults with severe disabilities. None of these resources are available through the Center on Human Policy, but may be obtained in several ways. Books and journal articles may be obtained through your local library, or through the Interlibrary Loan service of your library, if the library does not own the book or journal in question. Books, of course, may be ordered directly or through your local bookstore. Ordering information is given below for materials not available commercially.

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10. Salisbury, B., Dickey, J., & Crawford, C. (1987). *Service brokerage: Individual empowerment and social service accountability*. The G. Allan Roeher Institute. Downsview, Ontario, Canada.

Available through Human Policy Press:

Taylor, S.J., Racino, J.A., Knoll, J.A., & Lutfiyya, Z., (1987) *The nonrestrictive environment: On community integration for people with the most severe disabilities* outlines some basic principles of community integration, critiques the "continuum concept," describes homes and supports for children and adults with severe disabilities, discusses integrated work and covers the emerging controversies in community integration. To order write: Human Policy Press, P.O. Box 127, Syracuse. NY 13210. Price: \$8.95 plus 10% of the total or \$1.50, whichever is greater, for postage and handling. Make checks payable to Human Policy Press.

## CENTER RESOURCES AND REPORTS ON COMMUNITY LIVING

The Center on Human Policy, through its Research and Training Center on Community Integration, has developed a variety of reports and resources on the integration of people with severe disabilities into community life. The following reports explore the approach to community living described in this bulletin and are available for the cost of copying and postage. To get the full list of publications, please write: Center on Human Policy, Syracuse University, 200 Huntington Hall, Syracuse, New York 13244-2340. Orders may also be sent to this address to the attention of Rachael Zubal; remittance should include 10% of your order for postage and handling. All orders \$15.00 or more must be prepaid in U.S. currency unless an official institutional order form is submitted. Telephone orders will not be accepted. Checks must be made payable to the Center on Human Policy.

1. *Report on Centennial Developmental Services, Inc., Weld County, Colorado* (1987) describes the individualized ways in which people with disabilities are being supported in the community in this predominantly rural county. (40 pages) \$2.75

2. *Community Living in Three Wisconsin Counties* (1987) highlights Wisconsin's family support services program, their Medicaid Waiver Community Integration Program, innovative community living arrangements, county leadership and setting priorities for case management services. (52 pages) \$3.25
3. *Regenerating a Community: The Story of Residential, Inc., New Lexington, Ohio* (1989) tells the story of the people connected to this small agency in rural Ohio. (42 pages) \$2.70
4. *Community Living for Adults in North Dakota: A Case Study of an Apartment Program* (1989) describes community living services for adults provided in their own apartments by a non-profit agency under an individualized contracting process funded by the state's home and community-based Medicaid waiver. (45 pages) \$2.85
5. *Supporting Adults with Severe Disabilities in the Community: Selected Issues in Residential Services* (1988) examines ten issues in supporting adults in living in the community. (17 pages) \$1.75
6. *Caught in the Continuum: A Critical Analysis of the Principle of the Least Restrictive Environment* (1988) is a reprint of an article (*Journal of The Association for Persons with Severe Handicaps*, 13(1), 41-53) which reviews the origin of LRE,

analyzes the conceptual and philosophical flaws of LRE especially for people with severe disabilities, and contrasts integration with LRE as a guiding principle. (13 pages) \$2.78

7. *New Directions in Housing for People with Severe Disabilities: A Collection of Resource Materials* (1989) provides an introduction to housing strategies and resources that can be used to make all housing more accessible, and to increase the development and use of small, integrated housing options. \$2.70

8. Policy Analyses:

a. *A Policy Analysis of Private Community Living Arrangements in Connecticut* (1988) \$15.20

b. *A Policy Analysis of the Supported Housing Demonstration Project. Pittsburgh, Pennsylvania* (1987) \$4.45

c. *Moving into the 1990s: A Policy Analysis of Community Living for Adults with Developmental Disabilities in South Dakota* (1989) \$8.00

These analyses, written for state or local agencies, describe the findings of in-depth reviews of community living arrangements and make specific recommendations for moving to a "housing/support strategies" approach in each location.